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CONFERENCE REPORTS AND EXPERT PANEL

European Society of Intensive Care Medicine guidelines on end of life and palliative care in the intensive care unit

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Abstract

The European Society of Intensive Care Medicine (ESICM) has developed evidence-based recommendations and expert opinions about end-of-life (EoL) and palliative care for critically ill adults to optimize patient-centered care, improving outcomes of relatives, and supporting intensive care unit (ICU) staff in delivering compassionate and effective EoL and palliative care. An international multi-disciplinary panel of clinical experts, a methodologist, and representatives of patients and families examined key domains, including variability across countries, decision-making, palliative-care integration, communication, family-centered care, and conflict management. Eight evidence-based recommendations (6 of low level of evidence and 2 of high level of evidence) and 19 expert opinions were presented. EoL legislation and the importance of respecting the autonomy and preferences of patients were given close attention. Differences in EoL care depending on country income and healthcare provision were considered. Structured EoL decision-making strategies are recommended to improve outcomes of patients and relatives, as well as staff satisfaction and mental health. Early integration of palliative care and the use of standardized tools for symptom assessment are suggested for patients at high risk of dying. Communication training for ICU staff and printed communication aids for families are advocated to improve outcomes and satisfaction. Methods for enhancing family-centeredness of care include structured family conferences and culturally sensitive interventions. Conflict-management protocols and

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strategies to prevent burnout among healthcare professionals are also considered. The work done to develop these guidelines highlights many areas requiring further research.

Keywords: Intensive care unit, End of life, GRADE, Cultural variations, Decision-making, Palliative care, Communication, Family-centered care, Conflict management

Introduction

Death in the intensive care unit (ICU) usually occurs after treatment limitation decisions warranted by patient preferences or non-beneficial treatments [1]. The treatment plan shifts from a curative intent to end-of-life (EoL) and palliative care aimed at alleviating symptoms while also meeting the emotional, psychological, and spiritual needs of both the patient and the family [2, 3]. In the ICU, deciding to move from curative to EoL care is particularly challenging, because it involves withdrawing or withholding life-supporting treatments (LSTs) [3].

EoL care practices are shaped by ethical principles, legal frameworks, cultural norms, and available resources and therefore vary substantially across countries and healthcare systems [1, 4, 5]. Clinical teams share LST-limitation decisions with patients and families in some countries and make them alone in others [6]. Cross-country comparisons can help to improve practices by identifying correlations between specific EoL care patterns and outcomes. Some approaches emphasize patient autonomy and others a best-interest model [7]. No single approach is optimal for all patients, and clinical judgment is therefore needed to tailor EoL care decisions.

One objective of EoL care in the ICU is to support patients and families throughout the LST-limitation process in a way that fosters empathy and understanding, builds trust via effective communication, and provides support in initial stages of grieving [2, 9, 11, 12]. Timely shifting to EoL care as early as is warranted improves the experience of patients and families [8], who should receive continuous emotional support and frequent opportunities to voice their wishes and concerns [13, 14]. Interdisciplinary coordination helps to provide holistic care [11]. Finally, conflicts should be managed sensitively with special attention for and the well-being of the clinical team [16, 17].

The aim of this work was to develop guidelines for EoL and palliative care in the ICU, based on data published over the last two decades, including the corona virus disease 2019 (COVID-19) pandemic. The opinions of experts were sought when published evidence was inadequate. The goals of these guidelines are to improve quality of dying and death, minimize the adverse effects of the experience on families, support the well-being of healthcare professionals (HCPs), and serve as a resource for hospital administrators and healthcare policymakers.

Methods

Topic and panel composition

These guidelines were formulated by an international panel of experts on behalf of the European Society for Intensive Care Medicine (ESICM). The definitions of basic terms related to EoL in the ICU are summarized in Table 1. Seven domains were pre-defined and each was assigned to a group of experts in the panel. Each group was coordinated by a domain chair. A methodologist overviewed guideline development to ensure transparency of the methodology and reproducibility of the guidelines. Before each step of recommendation development, definitions, objectives, search strings, and study inclusion and exclusion criteria were determined. The definitions of recommendation strength were chosen before the recommendations were developed.

Research-question selection and literature search

For each domain, the relevant group formulated questions according to the Patients or Population-Intervention-Comparison-Outcome (PICO) format. Each PICO question was discussed and approved by the domain chair and group, methodologist, and full panel. For each PICO, two domain-group members performed a systematic literature search using the PubMed search engine, with pre-defined search strings and study inclusion and exclusion criteria. Each domain group chose to focus on randomized controlled trials (RCTs). When sufficient RCTs were not available, observational and qualitative studies could be included.

The quality of retrieved articles was graded according to the Grading of Recommendations, Assessment, Development, and Evaluations (GRADE) method (https://doi.org/10.1016/j.jclinepi.2010.04.026), by two members of the relevant domain group, with disagreements resolved by a third member or the methodologist.

When the PICO question allowed and RCTs were available, the methodologist was to perform a systematic review and meta-analysis.

Development of recommendations or expert suggestions

Each domain group formulated recommendations for each PICO based on the results of the literature review and meta-analyses. Three main criteria were considered: the certainty of the evidence as assessed by the methodologist, the Grading of Recommendations Assessment, Development and Evaluation (GRADE) level, and

Table 1 Definitions

Withholding treatment	Decision made not to start or increase a life-sustaining intervention
Withdrawing treatment	Decision that was made to actively stop a life-sustaining intervention presently being given
Active shortening of the dying process	Circumstance in which someone performes an act with the specific intent of shortening the dying process
Palliative care	Specialized medical care for people with a serious illness focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patients and their families
End-of-life care	End-of-life care includes the decision-making as to the limitation of life-sustaining therapies and the physical, emotional, social, and spiritual support for patients and their families
Advanced directives	A legal document that states a person's wishes about receiving medical care if that person is no longer able to make medical decisions; it may also give a person (such as a spouse, relative, or friend) the authority to make medical decisions for another person when that person can no longer make decisions (power of attorney)
Conflict	Dispute, disagreement, incompatibility, opposition, or difference of opinion involving more than one individual and related to the patient's management or to interpersonal conflict
Appropriate care	A patient care that is proportional to the expected survival and quality of life of the patient and in line with the patient's and relatives' values
Burnout	A psychological syndrome arising in response to chronic emotional and interpersonal stressors on the job and is characterized by three different features: emotional exhaustion, depersonalization, and lack of personal and professional completion
Decision-making	A stepwise practice of gathering and interpreting information, weighing different options, and ultimately taking a (shared) evidence-based and personalized decision

expert opinion. The proposed recommendations with the underlying summarized evidence were discussed by the full panel during meetings that were recorded to ensure accurate documentation. The results of these meetings were used to revise the proposed recommendations.

The final recommendations were submitted to a vote by the full panel. Approval of at least 80% of the panel members was required. It was planned that recommendations with lower approval rates were reformulated and re-submitted until at least 80% approval was achieved.

The final recommendations were categorized as high-level evidence (high level of evidence from two or more high-quality studies allowing a firm recommendation) or low-level evidence (low level of evidence from a single high-quality study or two intermediate-quality studies allowing a suggestion). When no high-quality studies and less than two intermediate-quality studies were available, the opinion of the panel experts was sought and the resulting recommendation was formulated as a suggestion ("expert opinion on clinical application").

The executive summary of recommendations and the evidence summary are shown in Tables 2 and 3, respectively. Evidence plot reporting findings in PICOs with low- or high-level evidence recommendations is depicted in Fig. 1.

Domain 1: Variability across countries

In critically ill adult patients, do countries or regions allowing withdrawal of life-sustaining therapies (LSTs) after initiation differ from countries or regions not allowing LST withdrawal in: (1) the time to first LST limitation? and (2) patient and family satisfaction with care?

Outcomes

- Time to the decision to withdraw LSTs.
- Patient and family satisfaction with care.

Background

Variations have been reported in the incidence of foregoing LST, time to LST limitation, and mortality after foregoing LST [1, 14–16]. In a study of European ICUs comparing EoL practices in 1999–2000 vs. 2015–2016, the more recent period was characterized by significantly higher proportions of foregoing LST and time reduction from ICU admission to the first LST limitation [1]. LST limitation was less common in low–middle-income countries (LMICs) than in high-income countries (HICs) [17]. The ICU EoL Practice Score (EPS) derived from the ETHICUS-2 study partly explains the substantial variation in treatment limitation decisions; furthermore, ICUs wishing to improve quality of end-of-life care may consider introducing the main weighted components: EoL protocols, palliative-care consultations, and local EoL legislation [18]. This score partly explains worldwide variations in LST limitations [1, 14, 15, 18].

Summary of the evidence

Legislation allowing LST limitations is associated with such limitations being implemented [1, 14, 15, 18]. Legislation fostering patient and family autonomy in EoL situations may contribute to greater patient/family satisfaction with EoL care [15, 18, 19].

Table 2 Executive summary of recommendations

DOMAIN 1. VARIABILITY ACROSS COUNTRIES		
Q1	**In critically ill adult patients, do countries or regions allowing withdrawal of life-sustaining therapies (LSTs) after initiation differ from countries or regions not allowing LST withdrawal in: 1) the time to first LST limitation? and 2) patient and family satisfaction with care?**	
1	Experts suggest that existence of national regulations regarding end-of-life (EoL) care allowing withholding or withdrawing LSTs may improve EoL care, optimize patient/family satisfaction, and enhance patient autonomy. Countries without such regulations may consider establishing legal provisions enabling LST limitation. This action should be supported/pursued by intensive care clinicians and their professional societies, lawmakers, and other key leaders.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION
2	Experts suggest that such regulations should incorporate patients' preferences (advance directives including living wills and power of attorney) as part of EoL decision-making.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION
Q2	**In critically ill adult patients, does being based in a low- and middle-income country (LMIC)/resource constrained environment compared to high income countries (HICs) alter approaches to EoL care?**	
1	Experts suggest that in critically ill adult patients, approaches to end-of-life care appear to differ between LMICs /resource-constrained environments and HICs across various domains.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION
DOMAIN 2. DECISION MAKING		
Q1	**In adult critically ill patients with an expected length of stay in the intensive care unit (ICU) of > 2 days do interventions aimed at having access to clarifying and documenting patient preferences and goals of care improve outcome?**	
1	Experts suggest that it is a prerequisite that family members have sufficient understanding of the patient's situation to be able to clarify goals of care.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION
2	Experts suggest assessing how patients and family members cope with the ICU situation to identify specific needs for optimal communication and personalized goals of care discussions.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION
Q2	**In adult critically ill patients for whom LST is deemed to be non-beneficial does the use of a structured EoL decision-making strategy improve outcomes?**	
1	Experts suggest that in adult critically ill patients for whom LST is deemed to be non-beneficial, implementing structured decision-making strategies may contribute to the understanding of surrogates about the care provided, eliciting the preferred role of surrogates in the decision-making process, and clarifying patient-centered goals of care.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION
2	Structured support and communication should probably be offered to surrogate following the decision to forgo ICU treatment in adult critically ill patients, to reduce complicated grief, anxiety, and post-traumatic stress disorder (PTSD) symptoms.	LOW LEVEL OF EVIDENCE
Q3	**In healthcare professional (HCP) staff who care for adult critically ill patients for whom LST is deemed to be inappropriate by the medical team does the use of a structured EoL decision-making strategy improve staff work satisfaction and decrease mental health symptoms?**	
1	Experts suggest the use of a structured decision-making strategy in critically ill patients for whom LST is deemed to be inappropriate. This approach might improve staff satisfaction and decrease mental health symptoms in HCPs.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION

Table 2 (continued)

DOMAIN 3. PALLIATIVE CARE		
Q1	**In ICU patients with advanced medical illnesses and deteriorating health in spite of optimal intensive care treatment, does early integration of palliative care reduce symptom distress, improve quality of life, and enhance alignment of care with patient goals?**	
1	Experts suggest that early palliative care including consultation with palliative care specialists for patients at high risk of morbidity and mortality in ICU might be useful in improving quality of life and enhancing alignment of care with patient goals.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION
Q2	**In patients with advanced medical illnesses and deteriorating health in spite of optimal intensive care treatment, does use of standardized tools for assessment of symptoms, compared to usual care, improve frequency of symptom assessment?**	
1	Validated instruments to assess symptoms should probably be used in patients with advanced medical illness to improve symptom detection and treatment.	LOW LEVEL OF EVIDENCE
Q3	**In critically ill patients from whom life-supporting therapies are withheld or withdrawn, does a protocolized approach to withdrawal of life support, compared to usual care without a protocolized approach impact outcomes?**	
1	Experts suggest that relatives of dying ICU patients may benefit from protocolized support, including family conferences before and after the death of the patient.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION
Q4	**In critically ill patients receiving life-supporting/intensive care therapies, does formal re-evaluation of these therapies in relation to the patient's evolving condition, prognosis, and achievable goals impact outcomes?**	
1	Experts suggest that regular re-evaluation of the proportionality of ICU LSTs with patients, family members, and multi-disciplinary teams, may reduce unwanted procedures in ICU and hospital lengths of stay.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION
DOMAIN 4. COMMUNICATION		
Q1	**In critically ill patients or their family members does an education program about EoL communication for ICU staff improve outcomes?**	
1	Structured training programs should probably be implemented for ICU HCPs to enhance competencies in EoL communication.	LOW LEVEL OF EVIDENCE
Q2	**In family members of critically ill patients, does receiving enhanced communication through brochure/leaflet/website/videos result in improved outcomes?**	
1	Enhanced communication written tools, such as brochures, pamphlets, or leaflets designed for the families of ICU patients, should be implemented in every ICU to complement standard oral communication.	HIGH LEVEL OF EVIDENCE
Q3	**In family members of critically ill patients does an intensivist team with training in palliative care skills, improve the outcomes?**	
1	An intensivist team with palliative care training should probably manage communication with families of critically ill patients dying in the ICU.	LOW LEVEL OF EVIDENCE
Q4	**In ICU patients or their family members, does having access to palliative/ethical interventions result in improved outcomes?**	
1	Experts suggest palliative care interventions might be useful for patients with poor prognosis in spite of optimal intensive care to improve patient and family member satisfaction with care.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION
Q5	**In critically ill patients at high risk of death, or in their family members, does a structured approach to EoL family meetings result in improved ICU outcomes?**	
1	A structured approach for conducting EoL family conferences should probably be used to decrease post-traumatic stress disorder in family members and to improve family satisfaction.	LOW LEVEL OF EVIDENCE

Table 2 (continued)

DOMAIN 5. FAMILY CENTERED CARE

Q1 In families of patients at high risk of dying in the ICU, do open/flexible visiting hours improve outcomes?

1	Experts suggest the use of flexible visiting to reduce family anxiety and improve satisfaction.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION

Q2 In patients for whom cardiopulmonary resuscitation is attempted in the ICU, does the option for family to witness the resuscitation effort improve family outcomes?

1	No formal recommendation nor expert opinion.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION OR AN EXPERT OPINION

Q3 In families of patients who die in the ICU, does follow-up bereavement support improve outcomes?

1	Bereavement brochures or leaflets combined with structured family conferences prior to death should be proposed to family of patients at the end of life.	HIGH LEVEL OF EVIDENCE
2	We suggest not routinely sending condolence letters, written by the ICU team, to bereaved family members.	LOW LEVEL OF EVIDENCE

Q4 In families of patients at high risk of dying in the ICU, do interventions that support families to be involved in providing or helping with patient care in the ICU improve outcomes?

1	Experts suggest that in end-of-life situations, encouragement of family-led care would be acceptable to family members and may be associated with better outcomes for caregivers.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION

Q5 In families of patients at high risk of dying in the ICU and unable to visit, do distance communication protocols (video calls etc) improve family outcomes?

1	No formal recommendation nor expert opinion.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION OR AN EXPERT OPINION

Q6 In families of patients at high risk of dying in the ICU, do interventions that address patients' and families' cultural needs improve outcomes?

1	Experts suggest that end of life situations should be tailored to the cultural needs of the patient and family where possible.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION

DOMAIN 6. INTERPROFESSIONAL COLLABORATION

Q1 In health care professionals providing EoL care does interprofessional decision-sharing improve outcomes?

1	No formal recommendation nor expert opinion.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION OR AN EXPERT OPINION

DOMAIN 7. CONFLICT AND BURNOUT

Q1 In ICU health care professionals do the conflict management strategies prevent conflicts related to the EoL situations?

1	Experts suggest implementing a protocol to prevent and mitigate conflict situations among HCPs or with family members.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION

Q2 In ICU healthcare professionals facing end of life care does implementation of preventive organizational or personal strategies mitigate the prevalence of burnout or mental distress?

1	Experts suggest promoting multidisciplinary communication in EoL situations and discussing goals of care within all parties involved: patient – family members – professionals, and to implement strategies preventing mental distress, including ethical discussions, in the ICU.	NO SUFFICIENT LEVEL OF EVIDENCE TO ALLOW A FORMAL RECOMMENDATION

Table 3 Evidence summary

Type of study	Number of studies according to level of evidence: Low to very low	Intermediate	High
DOMAIN 1. PICO 1			
RCTs			
Cohort studies	3		
Syst. reviews			
DOMAIN 1. PICO 2			
RCTs			
Cohort studies	3		
Syst. reviews			
DOMAIN 2. PICO 1			
RCTs			1
Cohort studies	3		
Syst. reviews			
DOMAIN 2. PICO 2			
RCTs			1
Cohort studies	2		
Syst. reviews			
DOMAIN 2. PICO 3			
RCTs			
Cohort studies	27		
Syst. reviews			
DOMAIN 3. PICO 1			
RCTs	2	1	
Cohort studies	7		
Syst. reviews			
DOMAIN 3. PICO 2			
RCTs	4	16	
Cohort studies	1		
Syst. reviews			
DOMAIN 3. PICO 3			
RCTs			1
Cohort studies	2		
Syst. reviews			
DOMAIN 3. PICO 4			
RCTs			
Cohort studies	9	1	
Syst. reviews			
DOMAIN 4. PICO 1			
RCTs	1	2	2
Cohort studies	4	1	
Syst. reviews			
DOMAIN 4. PICO 2			
RCTs	4	3	4
Cohort studies	5		1
Syst. reviews			
DOMAIN 4. PICO 3			
RCTs	2	2	1
Cohort studies	1		
Syst. reviews			

Type of study	Number of studies according to level of evidence: Low to very low	Intermediate	High
DOMAIN 4. PICO 4			
RCTs	2	2	
Cohort studies	1		
Syst. reviews			
DOMAIN 4. PICO 5			
RCTs	3	1	3
Cohort studies	3		
Syst. reviews			
DOMAIN 5. PICO 1			
RCTs	1		
Cohort studies	3		
Syst. reviews	1		
DOMAIN 5. PICO 2			
RCTs			
Cohort studies			
Syst. reviews	1		
DOMAIN 5. PICO 3			
RCTs		2	1
Cohort studies	9		
Syst. reviews	4	1	
DOMAIN 5. PICO 4			
RCTs			
Cohort studies	2		
Syst. reviews			
DOMAIN 5. PICO 5			
RCTs			
Cohort studies	2		
Syst. reviews			
DOMAIN 5. PICO 6			
RCTs	1		
Cohort studies	2		
Syst. reviews			
DOMAIN 6. PICO 1			
RCTs			
Cohort studies	5		
Syst. reviews			
DOMAIN 7. PICO 1			
RCTs			
Cohort studies	6		
Syst. reviews	3		
DOMAIN 7. PICO 2			
RCTs	1		
Cohort studies	5		
Syst. reviews			

Fig. 1 Evidence plot reporting findings in PICOs with low- or high-level evidence recommendations

1.1. Recommendations/expert opinion on clinical application

Experts **suggest** that existence of national regulations regarding EoL care allowing withholding or withdrawing LSTs may improve EoL care, optimize patient/family satisfaction, and enhance patient autonomy. Countries without such regulations may consider establishing legal provisions enabling LST limitation. This action should be supported/pursued by intensive care clinicians and their professional societies, lawmakers, and other key leaders.
No sufficient level of evidence to allow a formal recommendation.

Experts **suggest** that such regulations should incorporate patients' preferences (advance directives including living wills and power of attorney) as part of EoL decision-making.
No sufficient level of evidence to allow a formal recommendation.

Discussion

The EPS and several studies suggest that EoL legislation may promote the documentation of patient preferences in advance directives [14, 19] and good matching of EoL care decisions to patient preferences, notably regarding LST limitations [14, 18, 19]. Establishing advance directives and/or giving power of attorney to a healthcare proxy may facilitate discussions of EoL care preferences [20] and are key components of the recommended shared decision-making process [15, 21]. A lower number of LSTs at the end of life probably reflects greater respect for patient/family autonomy and is associated with greater patient/family satisfaction [22]. Consequently, intensivists, critical-care societies, and other leaders should promote the development of EoL legislation allowing LST limitation.

In critically ill adult patients, does being based in a low/middle-income country (LMIC)/resource-constrained environment compared to high-income countries (HICs) alter approaches to EoL care?

Outcomes

- Practice variation in LSTs.
- Knowledge and skills of HCPs in the field of EoL care.
- Experience of patients and family members.

- Healthcare costs.

Background

EoL care in critically ill patients has been assessed in several large studies, most of which were performed in HICs. EoL care practices in the ICU vary widely across the globe, and most patients live in LMICs, where results obtained in HICs may not apply [16, 23, 24]. Looking for differences in ICU EoL care between LMICs and HICs is therefore essential.

Summary of the evidence

Several electronic databases were searched for evidence on ICU EoL care in LMICs, published after 2000. Of the 57 identified publications, a 2022 scoping review and a study comparing LMICs vs. HICs across Asia were of particular interest [25, 26]. Of the 19 studies identified by the scoping review of data from LMICs, all were observational and none obtained information from patients or families [25]. ICU EoL care in LMICs has clearly not received sufficient research attention. The study comparing LMICs and HICs was a questionnaire survey done from May to December 2012 [26]. The respondents were 847 physicians in 255 ICUs in 10 LMICs and 618 physicians in 211 ICUs in six HICs. Major differences were noted between EoL practices between LMICs and HICs, in keeping with previous work by the same group [27]. However, according to GRADE, both studies produced only evidence of very low certainty [26, 27]. Scoping reviews cannot be assessed using GRADE.

1.2. Recommendations/expert opinion on clinical application

Experts **suggest** that in critically ill patients, approaches to EoL care appear to differ between LMICs/resource-constrained environments and HICs across various domains.
No sufficient level of evidence to allow a formal recommendation.

Discussion

Currently available data suggest that LMICs and HICs may differ regarding the use of LST limitations [26, 28, 29], HCP knowledge and skills in the field of EoL care [25, 29, 30], cultural factors influencing EoL care, specific environmental factors [25, 29, 30], patient and family views about EoL care (as shared by HCPs) [26, 29], and cost considerations [25, 26, 31]. ICU EoL care in LMICs is understudied.

Domain 2: Decision-making

In adult critically ill patients with an expected ICU length of stay > 2 days, do interventions aimed at having access to, clarifying and documenting patient preferences and goals of care improve outcome?

Outcomes

- Patient-centered care.
- Satisfaction with decision-making.
- Mental-health symptoms (depression, grieving, and post-traumatic stress disorder [PTSD]).

Background

Each patient should only be offered those ICU treatments whose expected effects are consistent with the patient preferences. The initial ICU management plan may be designed to cure a life-threatening illness, stabilize the patient while a treatment strategy is developed, or alleviate distressing symptoms. After a few days in the ICU, in addition to the treatment response, the match between the treatments used and the patient's preferences and values must be evaluated. These preferences and values must therefore be known to the ICU team. For patients without legally binding advance directives and/or legally appointed surrogate decision-makers, the relatives or close contacts act as sources of information and may legally act as surrogate decision-makers. However, during family meetings, discussions of patient preferences and values and realistic goals of care may not be straight forward [32]. The optimal time for initiating such discussions may not be obvious. In addition, family members face emotional struggles, notably grief and possibly guilt, when sharing decisions to limit LSTs [33]. A high level of communication and support, including transparent discussions about what is achievable in the context of the patient's preferences and values, is essential.

Summary of the evidence

In critically ill adults expected to require > 2 days in the ICU, elucidating patient preferences regarding the level of care is crucial for the patient, surrogate decision-maker, and HCPs. Formal family meetings were associated with greater satisfaction with the decision-making process but not with better overall satisfaction with the care provided [34]. In an RCT, a family-support intervention failed to decrease symptoms of anxiety and depression in families but improved families' ratings of communication and shortened the ICU stay [35].

Meaningful discussions of care goals require that families have a good understanding of LSTs, the level and intensity of support provided, and the patient's resuscitation status [3, 36]. Additionally, the ICU staff must

identify the coping strategies used by each patient and family [9].

2.1. Recommendations/expert opinion on clinical application

Experts **suggest** that it is a prerequisite that family members have sufficient understanding of the patient's situation to be able to clarify goals of care.
No sufficient level of evidence to allow a formal recommendation.

Experts **suggest** assessing how patients and family members cope with the ICU situation to identify specific needs for optimal communication and personalized goals of care discussions.
No sufficient level of evidence to allow a formal recommendation.

Discussion

In addition to legislation, religious beliefs and cultural norms may substantially influence EoL care decisions. Regardless of these influences, HCPs should elucidate patient preferences and values, adapt their communication and support strategies to individual patients and family members, negotiate conflicts, and determine appropriate goals of care. Communication skills are of considerable importance, notably for building trust in the pathway of care.

In adult critically ill patients for whom LST is deemed to be non-beneficial does the use of a structured EoL decision-making strategy improve outcomes?

Outcomes

- Patient/surrogate satisfaction with decision-making.
- Patient/surrogate mental-health symptoms (depression, grieving, and PTSD).
- Time to LST withdrawal.

Background

Decision-making for critically ill patients is a complex stepwise process of gathering and interpreting information, weighing different options, and reaching a decision, if possible in collaboration with the patient or surrogate [15]. A structured decision-making strategy may reduce variability and improve patient and surrogate outcomes, while also optimizing healthcare-resource utilization [37]. Depending on family preferences, cultural factors, and local legislation, the decision to limit LSTs is taken by the ICU team alone, by the surrogates, or as the result of a shared decision-making process reflecting individual patient preferences and values.

Summary of the evidence

LSTs can be considered non-beneficial when not expected to achieve survival or not consistent with the treatment goals chosen by the patient, surrogate, and/or HCPs. Good understanding of the situation by any surrogates involved in decision-making is essential [3, 36]. Surrogates differ in their ability and willingness to share decisions and should therefore be asked about their preferred level of involvement [38].

When there is consensus that LSTs are non-beneficial and should be withheld or withdrawn, structured support and communication are important to reduce the risk of complicated grief, anxiety, and PTSD symptoms in the relatives [39].

2.2. Recommendations/expert opinion on clinical application

Experts **suggest** that in adult critically ill patients for whom LST is deemed to be non-beneficial, implementing structured EoL decision-making strategies may contribute to the understanding of surrogates of the care provided, eliciting the preferred role of surrogates in the decision-making process and clarifying patient-centered goals of care.
No sufficient level of evidence to allow a formal recommendations.

Structured support and communication should probably be offered to family members following the decision to forgo ICU treatment in adult critically ill patients, to reduce complicated grief, anxiety, and PTSD symptoms.
Low level of evidence.

Discussion

Standardizing the complex EoL decision-making process is difficult and evaluating its effect on outcomes even more challenging. Neither the optimal decision-making strategy nor the most appropriate outcome measure has been identified to date. Methods for assessing how well the care provided matches the goals are needed. Other patient- and surrogate-related outcome measures (e.g., quality of communication, symptoms of anxiety and PTSD, decisional conflict) may be more strongly influenced by the result of the decisions than by the quality of the decision-making process (e.g., level of comprehension and whether needs for information and support were met). To improve healthcare-resource utilization, criteria that identify patients for whom LSTs are not goal-concordant or merely prolong the dying process would be helpful.

Communication is among the most important aspect of decision-making. Communication should be timely, frequent, and attuned to the needs and preferences of patient or surrogates. Spending more time with the patient or surrogate improves trust, thereby enhancing the shared decision-making process.

In HCP staff who care for adult critically ill patients for whom LST is deemed to be inappropriate by the medical team does the use of a structured EoL

decision-making strategy improve staff work satisfaction and decrease mental-health symptoms?

Outcomes

- Work satisfaction in ICU HCPs.
- Mental-health symptoms in ICU HCPs.

Background

In ICU HCPs, providing LSTs that are not consistent with patients' goals of care or that merely prolong dying is strongly associated with moral distress and intention to leave the job. The association is stronger in nurses than in physicians [40]. Moral distress may lead to conflicts, loss of trust, and loss of professional respect among team members [41]. Other consequences of moral distress may include depression, PTSD symptoms, burnout, and the loss of highly skilled ICU HCPs [42]. The appropriateness of LSTs and LST limitations therefore deserves close attention. Whether a structured strategy describing the components and timing of the decision-making process improves work satisfaction and/or decreases moral distress in ICU HCPs is unclear.

Summary of the evidence

No evidence on this point has been published. The recommendation below therefore rests solely on expert opinion.

2.3. Recommendations/expert opinion on clinical application

Experts **suggest** the use of a structured EoL decision-making strategy in critically ill patients for whom LST is deemed to be inappropriate. This approach might improve staff satisfaction and decrease mental-health symptoms in HCPs.
No sufficient level of evidence to allow a formal recommendations.

Discussion

Starting or continuing LSTs that are non-beneficial do not meet the patients' goals of care, or will merely prolong the dying process is strongly associated with moral distress among ICU HCPs [43]. Decision-making strategies should support HCPs, minimize subjectivity, and ensure that patients or surrogates express preferences, values, and desired goals of care. A structured approach is likely to benefit collaboration among HCPs and with the patients and families. The approach should ensure that the opinions, knowledge, and values of each participant are respected. Taking the different viewpoints of the ICU HCPs into consideration can improve the ethical culture in the ICU, thereby benefiting EoL decisions [44].

Domain 3: Palliative and end-of-life care in the ICU

In ICU patients with advanced medical illnesses and deteriorating health in spite of optimal intensive care treatment, does early integration of palliative care reduce symptom distress, improve quality of life, and enhance alignment of care with patient goals?

Outcomes

- Patient satisfaction.
- Completion of advance care planning.
- Transition to do-not-resuscitate/do-not-intubate.
- Number of transfers to hospice care.
- Patient anxiety, depression, and PTSD experience at three months.
- Transition from LSTs to comfort care.
- ICU length of stay.

Background

Given the high mortality among critically ill patients, palliative care must be available in ICUs. ICU HCPs as the main providers of palliative care with palliative-care consultants being called in for complex cases is the most common model [45]. For cancer patients, early enrollment in a palliative-care program, before hospital admission, was associated with better patient and family satisfaction, fewer hospital admissions, better quality of life, and achievement of the preferred place of death [46, 47]. Recent studies have sought to determine whether similar benefits are obtained in ICU patients and their families [48–50].

Summary of the evidence

Three single-center low- to very-low-level evidence RCTs from the United States (US) assessed a palliative-care consultation within 3 days after ICU admission of high-risk patients (e.g., with advanced age, lifespan-limiting chronic conditions, or moderate/severe acute conditions) [49–51]. The ICU stay was shorter and patient satisfaction better in one trial [50], while the other demonstrated more transfers to hospice care and fewer ventilator days and tracheostomies, with no difference in ICU stay length [51]. The results of seven observational studies of early palliative-care consultations or early family meetings to discuss patient goals support the findings from the RCTs [52–58].

3.1. Recommendations/expert opinion on clinical application

Experts **suggest** that early palliative care including consultation with palliative care specialists for patients at high risk of morbidity and mortality in ICU might be useful in improving quality of life and enhancing alignment of care with patient goals.
No sufficient level of evidence to allow a formal recommendation.

Discussion

Most studies of early palliative-care integration for ICU patients focused on consultation with palliative-care specialists or on family meetings with ICU staff to discuss goals of care. Other components of palliative care such as symptom management and spirituality were not investigated. Only three RCTs are available and both had a single-center design that may limit general applicability. The seven observational studies also had a single-center design, and five were retrospective.

In patients with advanced medical illnesses and deteriorating health in spite of optimal intensive care treatment, does use of standardized tools for assessment of symptoms, compared to usual care, increase frequency of symptom assessment?

Outcomes

- Discomfort, dyspnea, pain.
- Delirium.
- Thirst.
- Sleep and sedation.
- Anxiety and depression.

Background

Symptom assessment should be performed routinely, at regular intervals as opposed to only in response to distress, and documented [59]. Thirst, dyspnea, anxiety, fatigue, delirium, sleep, and pain should be evaluated using validated instruments. The presence of each symptom with its severity and any exacerbating and relieving factors should be recorded. Symptom assessment should continue after interventions [60].

Summary of the evidence

Of the 20 identified RCTs, most showed that routine symptom assessment with validated tools and documentation of the results increased the frequency of assessments and treatments [61–63]. Seven of the ten studies [59, 64–69] included in a 2015 systematic review [70] showed that introducing a pain-assessment protocol increased the frequency of pain assessments, improved significantly the documentation of assessment results, and increased the frequency of reports of pain. In a post hoc analysis of prospective observational data, regular pain assessments were associated with higher frequencies of assessments for sedation and procedural pain [71].

Fourteen RCTs assessed interventions aimed at improving sleep such as aromatherapy [72, 73], earplugs and eye masks [74–76], foot reflexology massage [77], and melatonin [78]. Most of these trials had fewer than 100 participants and were therefore graded as supplying only moderate-level evidence.

3.2. Recommendations/expert opinion on clinical application

Validated instruments to assess symptoms should probably be used in ICU patients with advanced illness to improve symptom detection and treatment.
Low level of evidence.

Discussion

Patient's with advanced medical illness and deteriorating health, despite optimal intensive care, frequently experience symptoms that adversely affect the quality of dying and death, the well-being of relatives, and the mental health of HCPs. Many trials and observational studies of symptom assessment are available, but none provides a high level of evidence. Low-level evidence exists about assessing a wide array of symptoms.

In critically ill patients from whom life-supporting therapies are withheld or withdrawn, does a protocolized approach to withdrawal of life support, compared to usual care without a protocolized approach impact outcomes?

Outcomes

- Symptoms.
- Opioid and sedative doses.
- Time to death.

Background

Practices for foregoing LST withdrawal vary across ICUs and are associated with the number of non-beneficial treatments and duration of the dying process. Several protocols about foregoing LST have been evaluated. The studies did not always quantify the effects of protocols on distressing symptoms, medication use, or time to death but provided some data of interest.

Summary of the evidence

A multicenter observational study comparing terminal weaning to immediate extubation in 402 patients found no differences in PTSD symptoms experienced by relatives [79]. In an observational study of only 14 patients, a nurse-led algorithm for terminal ventilator withdrawal was associated with better respiratory comfort compared to one-step extubation [80]. A multicenter cluster-randomized trial vs. standard care demonstrated a significant decrease in prolonged grief among relatives who had a family conference to prepare

for the imminent death, a meeting in the ICU room to provide support, and a meeting after the death [39].

3.3. Recommendations/expert opinion on clinical application

Experts **suggest** that relatives of dying ICU patients may benefit from protocolized support, including family conferences before and after the death of the patient.
No sufficient level of evidence to allow a formal recommendation.

Discussion

Although LST withdrawal is a crucial component of ICU EoL care, robust evidence about the effects of LST-withdrawal protocols on patients and relatives is not available. Rigorous clinical trials of protocols including routine symptom assessments and pharmacologic and/or nonpharmacologic management strategies are urgently needed. Relatives may benefit from protocolized support including family conferences before and after the death of the patient. There is no evidence that terminal weaning reduces PTSD among relatives compared to immediate extubation.

In critically ill patients receiving LSTs, does formal re-evaluation of these therapies in relation to the patient's evolving condition, prognosis, and achievable goals impact outcomes?

Outcomes

- ICU and hospital lengths of stay.
- Utilization of intensive-care interventions.
- Alignment of care with patient's goals.
- Triggers for palliative care delivery.
- Proportionality of ICU treatments.
- Clinicians' perceptions of excessive care.

Background

Few data exist on how intensivists make decisions about continuing or limiting LSTs. When the response to initial treatments is minimal and the prognostic scores intermediate, making the decisions that avoid non-beneficial interventions is particularly difficult [37]. A time-limited trial (TLT) can help [81]. The trial plan and duration should be agreed upon by the intensivists and patients and/or families. At the end of the trial, the appropriateness of continuing or limiting LSTs is assessed [82]. Other methods can be used.

Summary of the evidence

Eight observational descriptive studies [18, 37, 83–88] specifically evaluated TLTs. In addition, one before-after quality-improvement study assessed the impact of an early family conference [54]. An intervention that was designed to improve communication and involved both ICU HCPs and relatives used a TLT for care planning. The intervention improved the quality of family meetings, shortened ICU stays, and decreased treatment intensity and duration in patients less likely to benefit from aggressive management.

3.4. Recommendations/expert opinion on clinical application

Experts **suggest** that regular re-evaluation of the proportionality of ICU LSTs with patients, family members, and multi-disciplinary teams, may reduce unwanted procedures and ICU and hospital lengths of stay.
No sufficient level of evidence to allow a formal recommendation.

Discussion

The available data do not support any specific protocol about foregoing LST. No strong evidence exists that formal LST re-appraisal after a TLT is beneficial. Nonetheless, the experts agree that such a re-appraisal may benefit patients and families. There is some evidence supporting a multi-disciplinary approach, the involvement of patients or relatives in formal discussions with ICU HCPs, and the use of communication aids to enhance comprehension. RCTs are needed to assess whether a formal LST re-appraisal strategy affects patient, family, and HCP outcomes.

Domain 4: Communication

In critically ill patients or their family members does an education program about EoL communication for ICU staff improve outcomes?

Outcomes

- Patient and family satisfaction with communication.
- Mental-health symptoms.
- Better family/staff alignment with EoL decisions.
- Effective communication (empathy, active listening, non-verbal communication).

Background

Designing a communication-skills program for ICU HCPs requires time and resources. On the other hand, inconsistent, unclear, or non-empathic communication might decrease satisfaction with, and effectiveness of, information, especially at the EoL [89, 90]. Also, sharing decisions about the level of care between HCPs and families requires specific interpersonal skills.

Summary of the evidence

Studies of communication-skills programs for ICU HCPs have produced variable results. A single-center before-after study of patients who died in the ICU assessed a multifaceted intervention that included clinician education, local champions, academic detailing, feedback to clinicians, and system support [91]. Neither quality of dying as assessed by the family nor family satisfaction was different, but nurse-assessed quality of dying was better and ICU stays were shorter with the intervention. Another multifaceted program improved compliance with specific process measures reflecting communication with family members, although patient-specific outcomes were not significantly different [92]. A prospective, single-center study of weekly communication training (4 h in all) for internal-medicine residents on ICU rotation was associated with better family outcomes [93].

4.1. Recommendations/expert opinion on clinical application

Structured training programs should probably be implemented for ICU HCPs to enhance competencies in EoL communication.
Low level of evidence.

Discussion

Studies have assessed programs to improve EoL communication skills of ICU HCPs with the goal of better supporting families before, during, and after the death of their loved ones. These programs may contribute to reduce anxiety, depression, and PTSD symptoms among relatives. Communication and family satisfaction were consistently improved when communication was more closely centered on patients and families, based on their needs. Prolonged grief, anxiety, and PTSD symptoms were significantly less common [39]. However, family support by the interprofessional ICU team did not significantly decrease mental-health symptoms in relatives, despite better quality of communication and patient- and family-centeredness of care [35]. Importantly, baseline psychological distress of families differed between these two studies.

In family members of critically ill patients, does receiving enhanced communication through brochure/leaflet/website/videos result in improved outcomes?

Outcomes

- ICU experience.
- Satisfaction with EoL care.
- Mental-health symptoms.
- Family/staff alignment with EoL decisions.

Background

Comprehension and satisfaction are relevant criteria for evaluating the effectiveness of information communicated to family members of ICU patients [94]. Families unused to medical terminology may struggle to understand the diagnosis, treatment, and prognosis [36]. Brochures, leaflets, websites, and videos designed for individuals without medical training may improve communication.

Summary of the evidence

Printed information tools were effective in several studies [94, 95], including an RCT assessing a family information leaflet [94, 95]. A review of five RCTs not specifically focused on the EoL concluded that printed aids or structured family conferences with the usual ICU team improved comprehension and alleviated family distress while also decreasing the use of invasive treatments [96]. In a review of 19 ICU studies of EoL decision-making, communication aids were associated with better care-goals documentation and shorter mechanical ventilation times and ICU stays [97]. However, the quality of the evidence was low or very low.

4.2. Recommendations/expert opinion on clinical application

Enhanced communication written tools, such as brochures, pamphlets, or leaflets designed for the families of ICU patients, should be implemented in every ICU to complement standard oral communication.
High level of evidence.

Discussion

Printed communication aids within a proactive communication strategy significantly reduced symptoms of PTSD, anxiety, and depression in relatives while also increasing family satisfaction [96, 98, 99]. The content of these aids should be designed to resolve uncertainties about what is occurring and what is possible and to alleviate guilt among relatives.

Two RCTs assessed communication tools in the ICU but did not focus on the EoL. The use by nurses of tablets for communication was associated with increased satisfaction and comprehension in an RCT [100]. Adding daily written summaries of care to usual communication improved mental well-being and satisfaction among relatives starting at the second ICU week [101].

Combining brochures with a website improved comprehension and diminished stress among relatives in a before-after ICU study not focused on the EoL [102]. Inviting families to perform care rituals within 24 h after ICU admission of patients with a 30% predicted ICU mortality risk was associated with a lower prevalence of PTSD and anxiety symptoms after 90 days and with greater family-perceived

involvement in decisions [103]. However, handing relatives a list of questions to help elicit their concerns did not improve comprehension [104]. Families at risk for poor comprehension and greater distress, for instance due to language barriers, cultural specificities, or a low level of formal education should receive special attention [104].

In family members of critically ill patients does an intensivist team with training in palliative care skills improve outcomes?

Outcomes

- Family satisfaction with communication.
- ICU experience.
- Mental-health symptoms.

Background

Palliative care is a patient and family-centered strategy to optimize quality of life by anticipating, preventing, and treating suffering related to terminal illness. In the ICU, palliative care includes symptom control, supportive communication with relatives, and clarification of treatment goals. Intensivists may lack the specific knowledge and skills required to provide effective palliative care. Moreover, patient selection, palliative-care implementation models, and triggers for calling in palliative-care consultants remain debated.

Summary of the evidence

Education about ICU EoL care focuses on subordination of technological interventions to care goals, knowledge of prognostic factors and LST processes, trust-building communication with patients and families, skills in honoring cultural factors relevant to EoL decision-making, and emphasizing the importance for both patients and relatives of excellent palliative care [105, 106]. Simulation-based workshops on palliative-care communication skills significantly improved self-assessments of competence in communication [107]. Formal training in ICU EoL care was associated with less discomfort induced by LST limitations among junior intensivists [108]. Palliative-care education for nursing students improved their self-reported ability to deliver physical, psychosocial, and spiritual support to dying patients [109]. A palliative-care e-learning tool for physicians managing dying patients during the COVID-19 pandemic was associated with better self-reported knowledge but had smaller effects on attitudes toward death, including own mortality [110].

4.3. Recommendations/expert opinion on clinical application

An intensivist team with palliative care training should probably manage communication with families of critically ill patients dying in the ICU.
Low level of evidence.

Discussion

A quality-of-communication score [111] including items on EoL communication was significantly better in relatives who received a family-support intervention vs. usual support, although the primary outcome of mental-health-symptom burden was not diminished [35]. A review of RCTs indicated that printed communication aids and structured communication improves emotional outcomes of relatives and shorten ICU stays [96].

In ICU patients or their family members, does having access to palliative/ethical interventions result in improved outcomes?

Outcomes

Patient and family satisfaction with care.

Background

Access to palliative care interventions for patients receiving intensive care and their families has been studied for 2 decades, but the discussion has focused mostly on the effects on length of stay [112] or staff satisfaction with care. A recent review found a predominance of structural and procedural quality indicators for palliative care in intensive care units, and only few outcome indicators [113]. More specifically, information on patient and family satisfaction with palliative care interventions in intensive care units is lacking.

Summary of the evidence

Three studies [91, 114, 115] evaluated a pre–post-comparison on the implementation of a palliative care intervention. No study included a control group. The interventions included training of intensive care staff in palliative care, identification and training of local champions, identification of barriers, academic detailing and feedback to clinicians in two studies [91, 115] and early communication, family meetings, and social support in the third study [114]. All three studies were single site studies and included between 463 and 590 patients. All studies were rated as low evidence in GRADE.

Staff-rated quality of death improved significantly after implementation of a palliative care intervention, even though family-rated quality of death and family satisfaction showed only a trend that did not reach significance [91]. Family members were significantly more satisfied

with health care provider communication and competence, accessibility of information, involvement in decision-making, and reported higher overall satisfaction and satisfaction with the death and dying process after implementation of a palliative care intervention [114]. Social workers reported significant increase in the total number of activities for family members after the implementation of a palliative care intervention [113], even though family ratings of social workers were not improved.

In addition, the systematic review of Aslakson et al. [116] in 2014 included 37 papers with 30 palliative care interventions and showed beneficial effects with a decrease in hospital and intensive care length of stay, and no harmful effects, as (with one exception) the interventions decreased or had no significant effect on mortality. However, only 14 interventions reported the effects on family satisfaction, and only one of those studies [114] reported a significant improvement. Other significant findings such as decreases in nonconsensus between families and staff or in between intensive care team members, less family member PTSD and anxiety or an increase in the number of family meetings or the percentage of patient status changes to do-not-resuscitate are indicators of improved patient and family satisfaction in that review.

As few papers were available with only low-grade evidence, no formal recommendation can be formulated.

4.4. Recommendation/expert opinion on clinical application

Experts **suggest** that palliative care interventions might be useful for patients with poor prognosis in spite of optimal intensive care to improve patient and family member satisfaction with care.
No sufficient level of evidence to allow a formal recommendation.

Discussion

Several studies have demonstrated beneficial effects of palliative care interventions for critically ill patients in intensive care. However, these studies all were rated as low-grade evidence. Two studies focused on palliative care training of intensive care staff, and only one study on palliative care consultations.

Palliative care interventions should include palliative care training for staff, training of local champions for palliative care, regular interdisciplinary and multiprofessional case discussions on treatment goals and treatment and liason with a specialist palliative care service. More research is needed to evaluate the effects of palliative care consultations from a multiprofessional palliative care team on patient and family satisfaction with intensive care.

In critically ill patients at high risk of death, or in their family members, does a structured approach to EoL family meetings result in improved ICU outcomes?

Outcomes

- Mental-health symptoms.
- Family satisfaction.

Background

EoL meetings with families of patients dying in the ICU aim to protect the psychological and emotional well-being of families. Good comprehension of the medical situation and achievable goals, trust in the ICU team, and perceived empathy are crucial to avoid guilt and other forms of distress. Among structured approaches to EoL meetings, the VALUE method has been found effective [117, 118]. VALUE stands for Value and appreciate the sentiments expressed by the family, Acknowledge emotions, Listen actively, pose questions that foster a deeper Understanding of the patient as an individual, and Elicite questions from the family.

Summary of the evidence

High-evidence studies of structured EoL family meetings have shown variable effects on anxiety, no decrease in depression, and significantly fewer PTSD symptoms [35, 39, 98].

4.5. Recommendations/expert opinion on clinical application

A structured approach for conducting EoL family conferences should probably be used to decrease post-traumatic stress disorder in family members and to improve family satisfaction.
Low level of evidence.

Discussion

Three high-quality RCTs demonstrated that a structured approach to EoL family meetings significantly benefited the mental health of relatives [35, 39, 98]. However, since available high-quality studies were negative on most outcomes and as regard to the high heterogeneity, the level of the recommendation was downgraded.

Of note, a study in four ICUs assessing structured meetings with palliative-care specialists vs. usual meetings with the ICU team found no differences in anxiety or depression and more PTSD symptoms with the intervention [48]. ICU physicians are in frequent contact with families and may therefore be more able to develop a supportive relationship. Structured EoL family meetings led by ICU HCPs may protect relatives from anxiety and complicated grief, improve shared decision-making, and shorten ICU stays.

Domain 5: Family-centered care

Outcomes for the entire domain

- Mental-health symptoms.
- Family satisfaction with care and quality of dying and death.
- Staff satisfaction with care and the dying process.
- Quality of communication.
- Family satisfaction with decisions (including decisional regret).
- Intensity or costs of care (including length of stay).
- Palliative-care needs.
- Patient-centeredness of care.

In families of patients at high risk of dying in the ICU, do open/flexible visiting hours improve outcomes?

Background

Visiting policies for families vary across ICUs and countries. Many ICUs in northern Europe welcome visits around the clock, whereas restriction to a few hours a day is common in southern Europe. However, flexible visiting hours seem frequently offered to relatives of patients at high risk for dying.

Summary of the evidence

Studies of visiting policies in ICUs have not usually focused on the EoL. No high-quality evidence demonstrating that liberal visiting policies improve outcomes of patients and families have been published. A low-quality cross-over study found that allowing longer visiting hours did not decrease delirium in patients (primary outcome) but lessened anxiety and depression symptoms in relatives [119]. Other studies found greater family satisfaction with flexible visiting hours (defined as adapted to constraints experienced by families) compared to restrictive visiting hours [120–122]. A meta-analysis of observational studies and RCTs showed more ICU staff burnout with unrestricted visiting [121]. In a single-center before-after study, most patients and ICU staff were satisfied with flexible visiting [123]. A comparison of two ICUs with open vs. restricted visiting policies found no major differences in five outcomes of relatives, perhaps because only one of these (access to patients) was likely to be influenced by open visiting hours [123, 124]. Of note, most patients in these studies survived to ICU discharge.

5.1. Recommendations/expert opinion on clinical application

Experts **suggest** the use of flexible visiting to reduce family anxiety and improve satisfaction
No sufficient level of evidence to allow a formal recommendation.

Discussion

Visiting policies vary widely across ICUs [125]. Only low-quality evidence is available and, importantly, no studies focused specifically on EoL patients [126]. Moreover, no studies assessed patient outcomes.

In patients for whom cardiopulmonary resuscitation is attempted in the ICU, does the option for family to witness the resuscitation effort improve family outcomes?

Background

Cardiac arrest may occur in ICU patients at a time when their relatives are present. Whether relatives can benefit from witnessing resuscitation attempts is beneficial remains unclear.

Summary of the evidence

No high-quality data from ICU studies are available. A 2023 Cochrane review of RCTs in prehospital settings and emergency departments identified only two studies, both at high risk for bias [127]. The results suggest that witnessing resuscitation may decrease the prevalence of mental-health symptoms among relatives, without increasing stress among HCPs.

5.2. Recommendations/expert opinion on clinical application

No sufficient level of evidence to allow a formal recommendation or an expert opinion.

Discussion

No information on witnessing resuscitation attempts in the ICU has been published.

A position statement emphasizes the importance of supporting relatives of patients who experience cardiac arrest [126–128]. Assessing the willingness of relatives to witness resuscitation may be challenging given the time constraint. The relative should be accompanied and offered the opportunity to leave the room at any time. Presence of the relative must not interfere with resuscitation efforts or increase stress in the HCPs. Consequently, allowing relatives to witness resuscitation in the ICU may be best avoided until and if studies demonstrate that this practice is safe and beneficial for relatives, patients, and HCPs.

In families of patients who die in the ICU, does follow-up bereavement support improve outcomes?

Background

Bereavement support for families of patients having died in the ICU varies widely across ICUs and countries. Many ICUs offer anticipatory bereavement support at the time of LST-limitation decisions. Support may include structured family meetings and psychologist sessions during the ICU stay. Printed material providing information about what to expect when a loved one dies in the ICU can be given to relatives. Families can be invited to write diaries about their experience and to collect other memory-making material. Finally, after the death, families may be invited to come back to the ICU to discuss their experience.

Summary of the evidence

We identified 13 studies, all of low or very low quality [129–141]. Several of these studies assessed memory-making items, such as photos, word clouds, electrocardiograms (ECGs), and diaries collected before the death with the goal of easing the bereavement process. In an RCT, condolence letters sent to families did not decrease grief and may have worsened PTSD and depression symptoms [131]. A meeting shortly after the death was a component of a three-step strategy that decreased grief symptoms in another RCT [39]. A third RCT demonstrated that combining a structured EoL meeting with a brochure on bereavement lessened mental-health symptoms in relatives [98].

5.3. Recommendations/expert opinion on clinical application

Bereavement brochures or leaflets combined with structured family conferences prior to death should be proposed to family of patients at the end of life.
High level of evidence.

We suggest not routinely sending condolence letters, written by the ICU team, to bereaved family members.
Low level of evidence.

Discussion

The evidence supports combining a structured EoL meeting and a bereavement brochure. The meeting should include nurses, involve active listening, and help relatives express their emotions [98]. A meeting of the intensivist and ICU nurse with the family shortly after the death may be beneficial [39]. Memory- and meaning-making interventions deserve further study. At present, sending routine condolence letters is probably best avoided.

In families of patients at high risk of dying in the ICU, do interventions that support families to be involved in providing or helping with patient care in the ICU improve outcomes?

Background

Families play many active roles in the ICU, notably in EoL situations. However, involving families in EoL care raises practical issues. Moreover, the effect of family involvement on patients, families, and ICU staff must be considered.

Summary of the evidence

One observational [142] and one before-after [143] study were identified. Both provided only very-low- or low-quality evidence and neither was restricted to EoL care. The observational study [142] evaluated the preferences of 127 relatives regarding involvement in care. The most common preferred activities were communicating with the patient (93%), providing music (86%), and reading to the patient (85%). In contrast, oral suctioning, tracheostomy care, and endotracheal tube suctioning were preferred by only 32%, 25%, and 13% of relatives, respectively. Among relatives who stated wanting to provide music, to read to the patient, and to perform artwork with the patient, only 50%, 34%, and 6%, respectively, did so. No outcomes related to providing care were studied. The before-after study [143] was done in three ICUs, two in the US and one in Italy, and assessed rituals performed by relatives of patients with a greater than 50% risk of dying in the ICU. Families were given a booklet and explanation by a clinician about rituals they might want to engage in. The primary outcome of PTSD symptoms in the relatives 90 days after ICU death or discharge was significantly better with the intervention (adjusted odds ratio 0.54; 95% confidence interval [CI] 0.30–0.98).

The nurses reported that the proportion of families providing care increased with the intervention.

5.4. Expert opinion on clinical application:

Experts **suggest** that in end-of-life situations, encouragement of family-led care would be acceptable to family members and may be associated with better outcomes for caregivers.
No sufficient level of evidence to allow a formal recommendation.

Discussion

Family participation in care may be desirable but raises feasibility issues. Families must be authorized by the ICU team to provide care then receive continuous support during the care they provide. The involvement of families must not adversely affect patient safety or clinician well-being. Also, when offered the opportunity to provide

care, families should be made aware that they are free to refuse and to change their mind.

In families of patients at high risk of dying in the ICU and unable to visit, do distance communication protocols (video calls, etc.) improve family outcomes?

Background

During the COVID-19 pandemic, visiting policies were considerably restricted, including in EoL situations. Many ICU teams used remote systems to allow families to communicate with dying patients. Whether this strategy is helpful as part of usual practice deserves evaluation.

Summary of the evidence

We identified two studies, both done during the COVID-19 pandemic and both of very low or low quality. A cross-sectional survey with responses from 182 (54% of ICUs in the United Kingdom) documented use of virtual visiting in 97% of cases [144]. The staff felt that virtual visiting decreased psychological distress in patients and improved staff morale. Virtual visiting was deemed inappropriate for unconscious patients by 23% of ICUs and for dying patients by 7% of ICUs. Of note, restricted in-person visits to dying patients was usually allowed. No family outcomes were collected. A qualitative study done in France assessed themes of lived experiences in 19 relatives of patients who had died of COVID-19 in the ICU [145]. Communication was only via telephone calls. Relatives reported having difficulties establishing a relationship with the ICU team and experiencing feelings of abandonment, unreality, and disbelief.

5.5. Recommendation/expert opinion on clinical application

No sufficient level of evidence to allow a formal recommendation or an expert opinion.

Discussion

Restricted visitation during the COVID-19 pandemic may have adversely impacted family members. Virtual visiting is feasible [144]. No data on family outcomes associated with virtual visiting are available. Virtual visitation at the EoL is an important area for future research.

In families of patients at high risk of dying in the ICU, do interventions that address patients' and families' cultural needs improve outcomes?

Background

Many countries are multicultural, and culture affects attitudes toward dying and death [146, 147]. Many intensivists lack the knowledge and skills needed to take culture into account as part of patient- and family-centered care [148]. In addition to knowledge about other cultures, self-awareness of one's own attitudes, experiences, and even biases is required.

Summary of the evidence

Studies suggest the existence of cultural variability in terms of care and outcomes [149]. This applies to race, ethnicity, language, geography, or religion. A survey of 15 ICUs in the US showed that families from minority groups gave lower ratings for the quality of dying in the ICU [150]. In a cluster-randomized trial, also from the US, a mobile application that informed intensivists about family-reported needs induced a larger differential decrease in unmet needs among white families than among black families; the latter of which experienced a similar decrease in needs in both treatment and control groups [151]. In another US study, relatives of minority groups gave higher ratings for communication and care, although this finding seemed mediated by lower socioeconomic status [149, 150].

5.6. Recommendations/expert opinion on clinical application

Experts **suggest** that end-of-life situations should be tailored to the cultural needs of the patient and family where possible.
No sufficient level of evidence to allow a formal recommendation.

Discussion

ICU HCPs should seek to gain knowledge of the specific cultural mores and beliefs held by the population served by their unit. They should be mindful of any biases they may have and strive to develop a high level of respect for cultural differences. Awareness of cultural specificities is crucial when collecting patient and family preferences. Culture may affect reactions to specific care procedures and attitudes toward death.

Domain 6: Interprofessional decision-making

In HCPs providing, does interprofessional decision-sharing improve outcomes?

Outcomes

- Moral distress in HCPs.
- Conflict among HCP teams.

Background

EoL care in the ICU can be distressing not only to families but also to staff. Lack of effective involvement of HCPs can cause significant moral distress and within-team conflict.

Summary of the evidence

In qualitative interviews, seven nurses and four physicians in a single ICU described EoL decision-making as a balancing act involving teamwork, shared goals, good understanding of the points of view of all those involved, and awareness of one's own beliefs [152]. A study designed to develop a questionnaire identified seven factors influencing ICU HCP stress and ease of EoL decision-making, including collaboration and role clarity [153]. Psychometric testing found this questionnaire to be reliable and valid. A qualitative, focus-group study of ICU nurse and physician experiences when transitioning to EoL care indicated a need for better interprofessional implementation and acceptance of EoL care plans [154]. In another qualitative study, integrating palliative care within the ICU was perceived by HCPs as improving job satisfaction and collaboration among disciplines [153, 155–157].

6.1. Recommendations/expert opinion on clinical application

No sufficient level of evidence to allow a formal recommendation or an expert opinion.

Discussion

EoL care in the ICU places considerable stress on staff [158, 159]. While we may not have sufficient evidence, involving all members of the ICU team in EoL decisions would seem consistent with acknowledging the value of each. Studies are needed to design interprofessional decision-sharing interventions and to assess their effects on ICU HCP staff outcomes.

Domain 7: Conflict management and burnout

In ICU health care professionals do conflict management strategies prevent conflicts related to the EoL situations?

Outcomes

- Moral distress.
- PTSD symptoms.
- EoL-related ICU conflicts.

Background

Conflicts are common in ICUs, usually occur between nurses and physicians or among nurses, and are particularly frequent in EoL situations [12]. Conflicts are associated with mental ill-being among HCPs. Strategies to prevent and mitigate conflicts among ICU HCPs include staff meetings where all staff members can voice their opinions and feelings without being judged, role clarity, and a safe work environment.

Summary of the evidence

The typology of EoL-related conflicts has been described in several observational studies [12, 160]. Preventing ICU conflicts at the EoL is a key goal. However, no studies have identified interventions that prevent or mitigate EoL conflicts among ICU HCPs.

7.1. Recommendations/expert opinion on clinical application

Experts suggest implementing a protocol to prevent and mitigate conflict situations among HCPs or with family members.
No sufficient level of evidence to allow a formal recommendation.

Discussion

Evaluation of multimodal conflict-prevention strategies addressing organization, education, and communication would be welcome. Regular informal staff meetings may help to develop understanding and mutual acceptance of differing viewpoints within the ICU team could be helpful in preventing or resolving intra-team conflict and creating a safe working environment, especially in a multi-ethnic critical-care context [161].

In ICU healthcare professionals facing end-of-life care does implementation of preventive organizational or personal strategies mitigate the prevalence of burnout or mental distress?

Outcomes

- Burnout symptoms.
- Mental-health symptoms.

Background

Burnout syndromes are common in ICU HCPs [162, 163]. Risk factors include overwork, high stress, poor organizational support, poor teamwork, and limited autonomy [164–166]. Moral distress from perceived inappropriate care given to dying patients interacts with burnout [167]. Burnout is associated with anxiety, depression, substance abuse, and lower quality of care [168]. Job dissatisfaction is common among staff with burnout syndromes, who often leave the profession.

Summary of the evidence

A self-care and mindfulness program was used to promote wellness among ICU nurses [169]. A before-after

study showed that an intensive communication strategy about EoL care decreased the risk of burnout by 50% [170]. Both studies provided only very-low- or low-quality evidence.

7.2. Recommendations/expert opinion on clinical application

Experts **suggest** promoting multi-disciplinary communication in EoL situations and discussing goals of care within all parties involved: patient–family members–professionals, and to implement strategies preventing mental distress, including ethical discussions, in the ICU.
No sufficient level of evidence to allow a formal recommendation.

Discussion

Suggested strategies for preventing burnout include improved EoL care, conflict prevention, and participation in ICU research groups [171]. Research assessing these strategies applied to EoL care is needed.

General considerations

These guidelines aim to help ICU HCPs navigate the considerable challenges raised by EoL care. For many points of interest, few data are available. The considerable variability in practices and outcomes across ICUs and countries reflects this paucity of data and a need for further legislative and research efforts.

The strength of these guidelines is the establishment of a research agenda for the future, summarizing the literature of the last few decades and providing evidence-based recommendations and expert opinions about end-of-life and palliative care for critically ill adults for the benefit of the patients, families and HCP. On the other hand, these guidelines have limitations mainly due to the lack of high-quality studies, especially RCTs, which has prevented to generate bold evidence-based recommendations.

Communication within the ICU team and between the team and the patients and relatives is clearly crucial. Structured programs for ICU HCPs aimed at improving EoL communication have shown promise, although their long-term effects warrant further evaluation, with outcomes of interest including documentation of patient preferences, quality of dying, ICU length of stay, mental-health symptoms in relatives, and mental well-being of HCPs. Obstacles to good communication related to cultural, religious, and racial diversity deserve special attention. How legislation about EoL practices and the rights of patients and families may affect communication and well-being should be studied. ICU HCPs also need specific training in palliative care.

TLTs and other means of avoiding non-beneficial care in a manner that develops a consensus between the ICU team and the patient and family may be valuable for protecting HCPs from moral distress and patients from unnecessary suffering. Visiting policies, the collection of memory- and meaning-making material before the death, and follow-up bereavement support should be evaluated in high-quality studies as possible means of improving outcomes in relatives. Personal-care programs for ICU HCPs and well-being monitoring of staff by ICU heads also deserve investigation.

Conclusions

In conclusion, these guidelines present 8 evidence-based recommendations (6 of low level of evidence and 2 of high level of evidence) and 19 expert opinions (summarized in Table 3). Finally, limited availability of data is stressed and research priorities are identified.

Abbreviations

EoL: End of life; EPS: End-of-life practice score; HCP: Healthcare professional; HIC: High-income country; ICU: Intensive care unit; LMIC: Low/middle-income country; LST: Life-sustaining treatment; PTSD: Post-traumatic stress disorder; RCT: Randomized-controlled trial; TLT: Time-limited trial.

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Declaration

Conflicts of interest
AMi reports travel cost reimbursement for the ESICM 2022 and 2023 annual congresses. CC received honoraria for lectures, and support for attending meetings (NIH grants). He is also member of two DSMBs in the field of pall care and mindfulness. EA declares honoraria for Lectures from GILEAD, PFIZER, SANOFI, ALEXION and receipt of drugs for running a clinical trial (PFIZER). LH is President and CEO of Medical Corporation she has appeared, and her corporation has been paid for expert testimony in legal matters in Canada that pertain to allegations of negligence in critical care medicine in which patients have died. I have also been paid for expert testimony in a criminal case in EOL care in Canada. She received free admission to the ESICM 2023 meeting for all her work for ESICM not solely for this project. JD received payment for expert testimony in a criminal trial in Canada. 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